

TESTIMONY

SUPPORTING S. 2053 THE
COMMUNITY AND FAMILY LIVING
AMENDMENTS OF 1983

Presented by:

Minnesota Governor's Planning Council
on Developmental Disabilities

Before the:

Senate Finance Committee on Health
United States Senate
Minneapolis, Minnesota

August 13, 1984

The Minnesota Governor's Planning Council on Developmental Disabilities supports S. 2053, The Community and Family Living Amendments of 1983, including the changes and amendments recommended by the Association for Retarded Citizens - United States. In July of 1984, the Council adopted the following resolution:

S. 2053 COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

This bill provides expanded Medicaid coverage for family and community-based services for mentally retarded and other severely disabled persons. Its primary focus is severely disabled recipients of Supplemental Security Income (SSI). Federal Medicaid funds for institutional care would be phased out and redirected to more appropriate cost-effective home and community services, and this bill establishes new monitoring provisions and other protections.

: WHEREAS: The Community and Family Living Amendments of 1983 mandates long-range, systematic planning for community-based services systems while providing for an appropriate shift in Medicaid funding to support such planning; and

WHEREAS: The Community and Family Living Amendments of 1983 supports the idea that the place for people to build their futures is in the community; and

WHEREAS: The Community and Family Living Amendments of 1983 is a response to the needs of individuals by supporting an array of services which facilitate community integration and quality of services; and

WHEREAS: The Community and Family Living Amendments of 1983 establishes new monitoring provisions and other protections for people with disabilities living in the community.

THEREFORE BE IT RESOLVED: The Governor's Planning Council on Developmental Disabilities supports the bill with its recommended changes, proposed by the National Association for Retarded Citizens, and expanded eligibility requirements to include persons with mental illness and other disabilities.

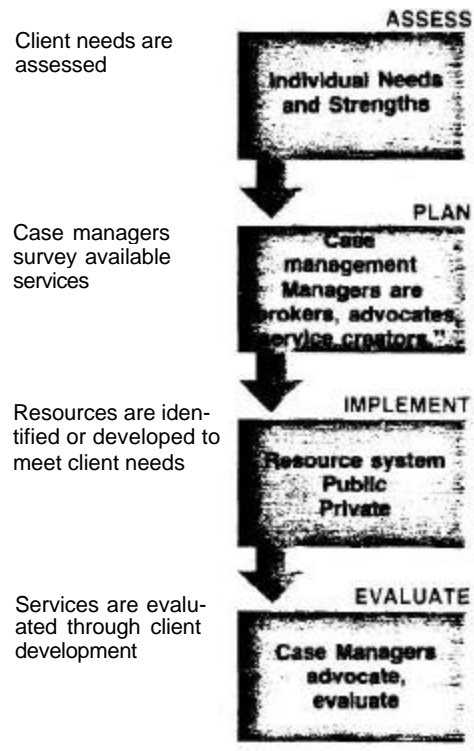
The introduction of S. 2053 provides an opportunity to examine several issues surrounding services especially residential services for persons with developmental disabilities.

The Minnesota Governor's Planning Council on Developmental Disabilities welcomes this opportunity to discuss the issues and offer observations about the current service system in Minnesota. 1. Consumer-Driven System

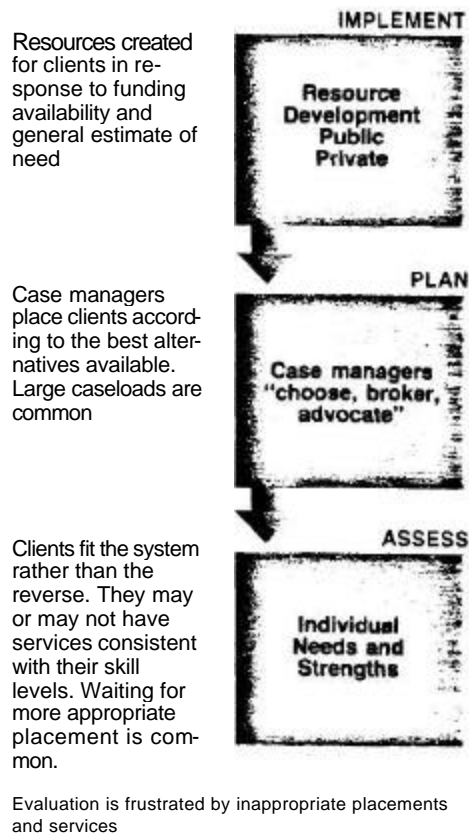
Overreliance on construction of facilities or the maintenance of an already existing service may inadvertantly direct public resources to meet the needs of a system (bricks and mortar) rather than the needs of people. To be responsive to an ever-changing profile of clients, the service system itself must adapt and be capable of change. ICF-MR facilities should be viewed as one type of service within a broader array of programs and services available to people with developmental disabilities. Those services should remain flexible and promote, wherever possible, movement into more independent (usually less costly) settings. To achieve those ends, funding mechanisms should accommodate people; not programs. (Policy Analysis Series Paper #15, March 14, 1983.)

In Minnesota, individuals are made to fit services rather than services designed for individuals. The difference between "consumer powered" and "resource or provider-driven" system is illustrated as follows:

CONSUMER-POWERED SYSTEM



RESOURCE-POWERED SYSTEM



S. 2053 recognizes and supports the empowerment of consumers and places high priority on families. This is the first time that Congress has recognized the family and small community settings as the option of first choice. Meeting Demands for

2. Service

Much of the demand for community placements in Minnesota could be met by existing ICF-MRs if appropriate alternative services for many current ICF-MR residents were developed and adequately

funded. For many people, ICF-MR services may be the most appropriate service model; for others, that level of service may represent only one step in a process of growth and change. Quality Assurance Review (QAR) data suggest that as many as 200 people now living in group homes in Minnesota are ready to move into semi-independent living settings; other estimates indicate that, with varying levels of supervision, as many as 1,000 people could be placed into foster care or semi-independent living programs (Copeland and Iversen, 1981). S. 2053 allows flexibility in the service system to meet needs in a range of alternative living arrangements. 3. Size of Community Facilities

Size of facilities remains an issue. Current studies by the Minnesota Developmental Disabilities Council (Policy Papers #4, #15, #19) indicate that the smallest facilities are not the least costly. Several mitigating factors should be considered, however. Most of the smallest ICF-MRs are relatively new facilities. Inflation and the recent increases in the costs of construction and financing may account for much of those cost differences. Additionally, people now being placed into community facilities are more likely to have lower levels of functioning and/or physical handicaps than people placed several years ago in older facilities. Higher resident dependency levels suggest higher staff-resident ratios; hence, increased costs. Finally,

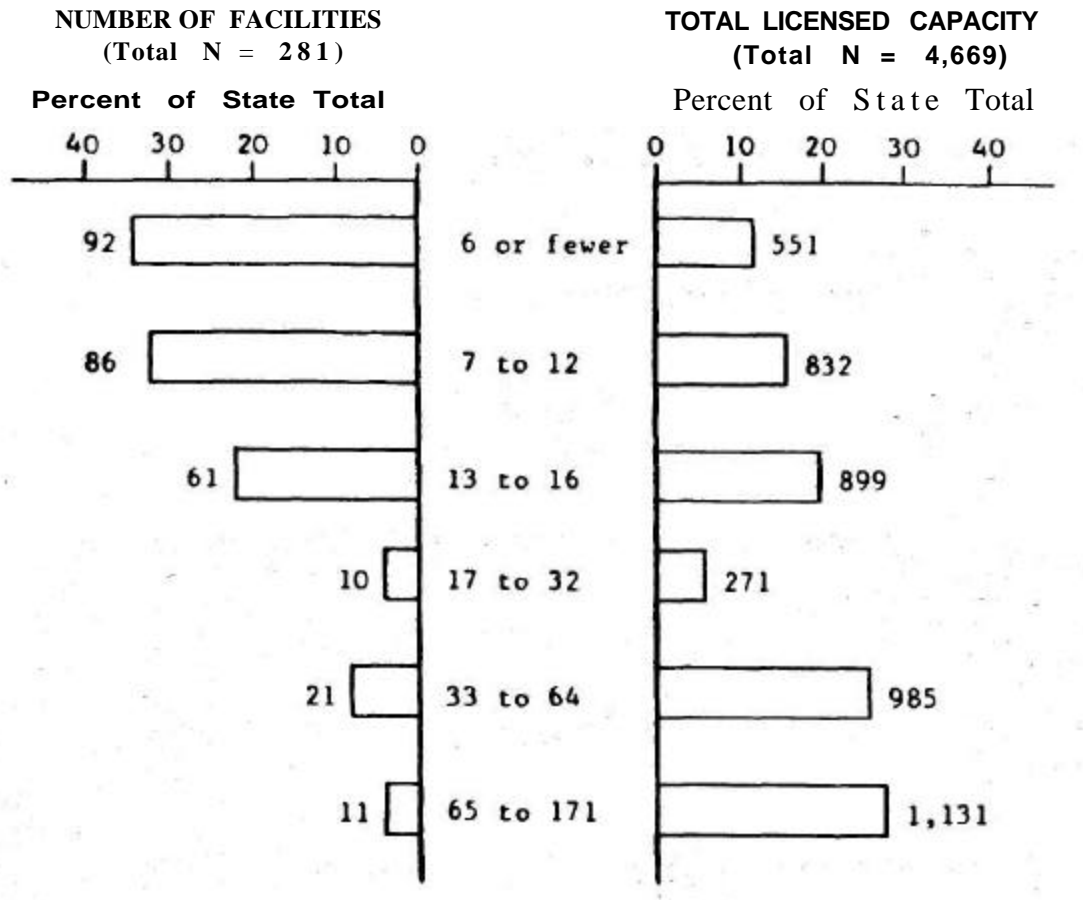
the literature suggests that when all factors are considered, the psychosocial and developmental needs of individual residents are more likely to be met in small, homelike residential programs, rather than in larger facilities. Such factors include:

- individualized attention (Baroff, 1980)
- resident oriented care practices (Balla, 1976; Baroff, 1980; King, Raynes & Tizard, 1971; McCormick; Balla & Zigler, 1975)
- absences of security features, existence of personal effects, privacy in bathroom and bathroom areas (Balla, 1976; Baroff, 1980)
- community exposure, social interaction (Crawford, 1979; Baroff, 1980)
- experienced, trained direct care staff (Bellinger & Shope, 1978; Baroff, 1980).

4. Larger Community Facilities

The appropriateness of larger community ICF-MRs also needs to be addressed. In 1980, the ten largest facilities in Minnesota accounted for nearly one-quarter of the total community ICF-MR bed capacity. Some facilities exceed the size of state hospital programs. In 1980, nearly half (49%) of the people in community-based ICF-MRs lived in "group homes" with more than 32 residences. The figure below graphically depicts the size range of Minnesota facilities.

FACILITY SIZE



Developmental Disabilities Program, Policy Analysis Series
 PAPER No. 19: An Update to Policy Analysis Series No. 4 and
 15: Cost Function Analysis of Minnesota Intermediate Care
 Facilities for Mentally Retarded (ICF-MR) Per DIAMS: 1981
 (St. Paul, MN: Developmental Disabilities Program, State
 Planning Agency, August 14, 1983).

5. Less Costly Alternatives

Community ICF-MR programs are not cheap. In fact, the costs of a community placement for a former state hospital resident may approach those of the state hospital system—when costs of day

programming and support services are included. This is most true for children. Residential and day programs for children are relatively more expensive than adult programs. Consideration should be given to developing in-home support services and expanding family subsidies for children. Not only are these programs more cost-efficient, but they may help to forestall or alleviate the need for placements into costly institutional and ICF-MR settings.

We are extremely pleased with the concept of the Title XIX Home and Community Based Waiver. While the provision of these services under the Medicaid Waiver is important in the development

V_ of less costly alternatives, only a limited number of people can be served by specific types of services such as supported living arrangements and in-home supports. One useful service not covered by the waiver in Minnesota is Semi-Independent Living Services (SILS). The provision of SILS involves placement of adults in small units (2-4 people) where they are supervised by a licensed agency and provided with services based on need, including training in cooking, shopping, hygiene and using public transportation. The purpose of SILS is to train for independence or to maintain individuals in semi-independence. SILS room and board are paid from the following sources: Supplemental Security Income (SSI), Minnesota Supplemental Aid (MSA), Social Security

Section 8 (HUD), General Assistance (GA), wages, food stamps, and combinations of these. As of December 30, 1983, there were 67 licensed SILS agencies with a total capacity of 1,290 persons in Minnesota. Shifting use of Medicaid dollars as proposed in S. 2053 would permit expansion of services like those available under the waiver and the development of other services such as SILS which allow for increased independence of persons who are mentally retarded. Further, they are compatible with cost considerations and consistent with policy statements which promote normalization and least restrictive living environments. 6. Support Services

The further development of ICF-MR programs, as well as other community-based residential care programs, cannot proceed without also considering the availability and appropriateness of community support services. There are at least two major areas of concern: (1) the availability of day programs and (2) adequate case management services. A. Adequate and Appropriate Day Programs

The ultimate success of residential care services is highly dependent upon the availability of appropriate day programs-- programs committed and geared toward client growth and development in self-help skills, academics, vocational skills, and meaningful employment. Current opportunities are limited. Data indicate that many potential clients are waiting to participate in developmental achievement center

programs. At the same time, current DAC participants are ready to move into sheltered workshops but are unable to make those transitions because there are no vacancies (Policy Analysis Paper No. 8, 1982). Future development of community residential programs must be closely tied to the availability of quality day programs which are capable of meeting the individual needs of residents. B. Case Management

Finally, the success of community programs is also dependent upon an adequate supply of case management services. In a system of care which is becoming more and more decentralized, it is imperative to have in place and operating a workable case management system (i.e., reasonable caseloads) which can help ensure that appropriate programs and services are available, that necessary services are provided, and that quality of programs is maintained. Few places in Minnesota have adequate case management services. 7. Target Population

We fully support the definition of developmental disability in S. 2053. We are concerned that two groups be considered for inclusion: emotionally disturbed children and mentally ill persons. If S. 2053 cannot address these groups, then we urge Congress to consider the needs of these persons in the near future.

Conclusion

A belief in human dignity, that each person is unique and capable of development underlies protection of the basic rights of individuals. While the majority of people with disabilities live independently, some people need either temporary or long-term help from society. S. 2053 as proposed provides an excellent opportunity for society to explore more cost-effective, less restrictive methods of care for persons with developmental disabilities. The attached document "Position Statement on Service Provision to Developmentally Disabled People" further defines our Council's position.

REFERENCES

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Minnesota Governor's Planning Council on Developmental Disabilities

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POSITION STATEMENT ON SERVICE PROVISION TO DEVELOPMENTALLY DISABLED PEOPLE - 1982

Changing social and political priorities require a social service system to frequently restate its fundamental ideology. The ideology clarifies the purpose and importance of the goals and objectives. A community appraisal of the ideology will clarify whether the commitment to these ideals remains or if other priorities have been established.

The ideology of the Minnesota Governor's Planning Council on Developmental Disabilities includes the following:

1. **INDIVIDUAL VALUE:** Our nation has proclaimed that all persons have basic rights including those to life, liberty, and the pursuit of happiness. This commitment is based on political, philosophical, and theological beliefs that each person is fundamentally equal. Over the last two centuries, disenfranchised groups have become recognized as contributing citizens. The Governor's Planning Council on Developmental Disabilities is committed to the recognition of value of individuals who are developmentally disabled. Every person has the right to equal respect, dignity, rights and responsibilities.
2. **DEVELOPMENTAL MODEL:** Every person is capable of growth and development regardless of the severity of his or her handicapping condition. An individual continues to grow as long as habilitative opportunities exist and are not limited to specific chronological ages.
3. **THE NORMALIZATION PRINCIPLE:** Individuals, by definition, are unique from one another. These differences can be reduced or intensified depending upon the education and experiences of both individuals and society. The normalization principle draws from the belief that the individual's ability to contribute to society is directly related to his or her opportunities to participate in the society.
4. **CONSUMER PARTICIPATION:** Maximum consumer involvement in determining needs and services will increase the effectiveness of the services. The consumer knows his/her own needs best, and establishing accountability of service delivery systems with consumers and their representatives can lead to higher quality services.

Statement of Objectives

The basic guidelines for a service system are the formal goals, those which "are the designated, chartered, and manifest intents of an organization.

These goals represent what the organization is designed to accomplish, its reason for being, and its objectives for society and for the population or clientele it serves" (Miringoff, 1980). Clearly stated objectives communicate to the clients served, the service staff, and the community at large the direction and purpose of the work undertaken. They provide a critical tool for evaluating the daily activities to the fundamental ideology.

The following objectives represent the proposed direction of the Governor's Planning Council on Developmental Disabilities:

1. To obtain or provide services at local levels so that people who are or become developmentally disabled can remain in or return to their communities.

Therefore, it is our position to:

- a. Encourage the provision of services at the local level so that all disabled persons will be able to be served in a community based program regardless of the severity of the handicap or complexity of the needs.
 - b. Encourage local programs to plan and support a "zero reject" orientation toward persons in need.
 - c. Encourage the provision of services as close to home as possible and in an environment which imposes the minimum stigma and external control upon each individual.
 - d. Encourage the prevention of all unnecessary admissions or readmissions to institutions.
 - e. Encourage the provision of services in the "least restrictive alternative."
2. To encourage the provision of an array of specialized services which meets the needs of Minnesotans from birth until death.

Therefore, it is our position to:

- a. Give early intervention primary consideration.
- b. Encourage communities to develop a full range of services to meet the developmental and human needs of all persons with developmental disabilities.
- c. Encourage the provision of services which are specialized to meet unique needs.
- d. Encourage the involvement of separate and different settings and locations consistent with the function of the services (vocational programs in industrial settings, residential programs in residential settings, etc.).
- e. Provide proper linkages, continuity and cooperation between elements of the service system in such a way as to minimize barriers that interfere with clients receiving proper care.

f. Encourage the provision of access to appropriate services without regard to the nature, severity or multiplicity of needs, and without regard to race, sex, physical handicap, age or economic status.

3. To promote the development of services for developmentally disabled persons through the use of generic resources and settings available to all citizens.

Therefore, it is our position to:

- a. Advocate for the rights of our clients to use the same resources and settings which are available to all citizens, whenever those resources and settings are appropriate to meet the individual's needs.
- b. Coordinate with programs in the community to identify needs of persons with developmental disabilities, identify roles and responsibilities of agencies, and develop a plan for meeting service gaps.
- c. Encourage "direct services" only to eliminate gaps within existing programs.
- d. Promote the integration of developmentally disabled people into the community in all facets of their lives.
- e. If necessary provide training and resources to staff and generic agencies who will serve developmentally disabled people.
- f. Make information available to consumers, parents, and staff on community resources.

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4. Through the use of individualized program plans, to develop the skills of "developmentally disabled people so that they may participate in and contribute to their community.

Therefore, it is our position to:

- a. Encourage counties to provide clients with appropriate individual service plans based on an adequate assessment of needs.
- b. Encourage providers to give opportunities to develop in clients their potential to become more self-sufficient and to attain self-confidence and dignity.
- c. Encourage the state and county to provide the appropriate protective and follow-along services when needed.
- d. Recognize that each person is unique, and be responsive to the individual differences and needs of our clients.
- e. Utilize modern, well-researched, effective and humane educational and therapeutic techniques, services and service models.
- f. Develop programming for each individual, rather than for groups or facilities.

- g. View developmentally disabled persons as rightful members of the community, with strengths as well as weaknesses, and always with potential for growth, participation, and contribution.
 - h. To increase the individual's competence in the areas of independent functioning, economic activities, physical development, vocational skills, domestic activities, cognitive skills, language and communication, socialization, responsibility and self-direction.
 - i. To reduce the frequency of socially unacceptable behavior such as violent and disruptive behavior, withdrawal, anti-social behavior, and self-abusiveness.
5. To support and assist families in meeting the needs of the developmentally disabled family member.

Therefore, it is our position to:

- a. Maintain the family relationship through childhood, including adolescence.
 - b. Provide support for adult growth and independence as normal as possible.
 - c. Coordinate with families to identify developmental disabilities, identify roles and responsibilities of the family and the agencies, and provide assistance directly to the home whenever appropriate.
 - d. Provide or procure training, if necessary, to assist families in meeting the specialized needs of the family member with a developmental disability.
 - e. Make information available to families on the resources available within the community to meet the needs of the developmentally disabled person.
 - f. Provide "direct residential services" only when assistance provided to the natural home is determined to be inappropriate.
 - g. Aid the family in recognizing the disability as an independent event, not a negative reflection on the family nor the developmentally disabled individual.
6. To increase the public's understanding of the ability and needs of persons with mental retardation.

Therefore, it is our position to:

- a. Improve the image and acceptance of disabled (and potentially devalued) people through the education of the public. Recognize that social perceptions and prejudices may be as limiting as the individual's developmental disability.

- b. Recognize the contributions made by disabled persons to their own community through public education activities.
 - c. Focus on the special needs of disabled persons and their families through public education.
 - d. Provide public education in a manner which will enhance the image of persons with developmental disabilities.
 - e. Respect the rights and dignity of each individual in public education activities.
7. To advocate for the rights and responsibilities of citizenship for developmentally disabled persons.

Therefore, it is our position to:

- a. Encourage the provision of services in such a way that each person has the opportunity to exercise as many civil, legal and human rights as possible.
 - b. Support clients in exercising maximum responsibility for their lives so that they may function as autonomously as possible and participate in decisions regarding their lives to the greatest possible extent.
 - c. Provide services in the least restrictive manner possible.
8. To provide staff with the support and training necessary to fulfill their professional responsibilities.

Therefore, it is our position to:

- a. Encourage systematic recruitment of high quality professional staff and help all employees improve their ability to perform their jobs through education and training.
 - b. Encourage the provision of steady employment at a salary commensurate with the service provided by the employee.
 - c. Encourage the provision of pleasant work surroundings including a safe and healthful working environment.
 - d. Encourage the provision of opportunities for advancement to existing personnel.
9. To provide an administrative structure which is consistent with the purpose, goals and positions of the Governor's Planning Council on Developmental Disabilities.

Therefore, it is our position to:

- a. Encourage state agencies to provide for an equitable distribution of services.

- b. Encourage state agencies to provide policy and program standards in order to maintain the quality of services.
10. To provide for a systematic planning, evaluation, review, assistance, and resource development process consistent with the purpose, goals, positions, and priorities of the Governor's Planning Council on Developmental Disabilities.

Therefore, it is our position to:

- a. Plan in such a way as to place the maximum decision-making power as close to the client as possible.
- b. Encourage monitoring systems to ensure that rights are protected and habilitation needs are being effectively met.
- c. Plan in cooperation and coordination with the planning efforts of existing and ongoing planning groups within the Department of Energy, Planning and Development and other state and local agencies.